

Research Case Study: Partnering with Health Consumers In Analysis of Research To Improve Hospital Test Result Management – Part 3: Ben – A participant in the workshop

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Upcoming Events

What Involving People in Research Can Look Like – Sydney 11Dec19
(<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part3/>)

December 11 @
10:25 am - 1:30
pm UTC+11

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Ryde Eastwood
Leagues Club
(<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part1/>), and Part 2, Maureen (a patient advocate) (<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part2/>), talked about their experiences of a research data analysis workshop run by Mary to get health consumer input into the analysis of her research project data. In this final Part 3, another health consumer participant, Ben Steele, share's his experience of the workshop and why he got involved.

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In Part 1, Dr Mary Dahm (a researcher) (<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part1/>), and Part 2, Maureen (a patient advocate) (<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part2/>), talked about their experiences of a research data analysis workshop run by Mary to get health consumer input into the analysis of her research project data. In this final Part 3, another health consumer participant, Ben Steele, share's his experience of the workshop and why he got involved.

Ben, can you tell us a little about your background?

I changed from a successful career in the building & construction industry to project management and consumer work within the health system about 5 years ago. I now also have my own related consulting business "Will2evolve" and do a mix of work in the health sector, mainly related to working with AOD (Alcohol and Drug) Services and Mental Health.

What brought you into doing that?

When I took some time out from the building industry, I actually got qualified for commercial boating and did some work in Maritime industry for a while. At the same time I was scouring the internet for other opportunities and saw one at South Eastern Sydney Local Health District Drug and Alcohol Services on a consumer participation project. I applied, and got a start. I had some lived experience in that area and was happy to transition into a new field and new paid vocation.

Since then, I saw an opportunity to work in a consulting capacity around Australian Commission for Quality and Safety in Healthcare's (ACQSHC) Standard 2 (Partnering with Consumers) and am currently working with >10 different organizations on related projects, committees and education.

In the beginning, when I went to do consumer work, I did the consumer training with Health Consumers NSW. That was a good opportunity for professional development and networking.

So how did you hear about Mary's workshop?

I think it was off the Health Consumers NSW website. They always advertise, get different opportunities on there, so I put in an expression of interest to Mary. We then had a bit of a phone call, gave a bit of my background and she got me enrolled.

So why were you interested in being involved?

I've got interest in little bits and pieces with universities and academia about what's emerging, different research projects and sort of trying to broaden my work mix as well. It's interesting.

What training have you had that has been helpful?

I have a double degree in Business Management Marketing. And in the years I was working at SESLHD Drug and Alcohol, I got heaps of other training, such as training around primary health care and harm minimisation. I also trained up to be a Peerzone facilitator (training and education around mental health wellbeing).

What were your expectations going into the day?

Given the topics, I thought it was going to be pretty dry 3 hours, but it was more than that. But it actually was a really well run little session. And there was a few other attendees from the Prince of Wales Consumer Advisory Committee there. So I sort of knew a few people, plus Anthony from Health Consumers NSW. It was just sort of brainstorming work around two different topics and I was really encouraged by the quality of the whole thing. It far exceeded my expectations.

So what was it about it that you thought made it well run, professional? What were the things that stood out to you?

I think Mary, just her contact prior briefing us was good. The fact that they did remunerate us for participation was good, including cab charges. That was helpful, because it was out in Ryde. The set up of their space there was nice too. It was a nice room. We all got split into groups with different people from the Health Sector. I'm just trying to reflect back here. They gave us a good overview at the start, of why we were doing it. Time keeping wise, it was kept to time. And just the process of brainstorming with other health workers in small groups, and then reporting back to all the attendees – it was a good process.

I think they were recording the session too so they were taking notes. They were trying to extract all and every bit of information, related to those topics that they could. I think a lot of our comments were sort of put down on line notes and brainstormed. Yeah, it was good.

So you felt like they were listening and really taking on board feedback?

Yeah, for sure. They were pretty broad-brushed, high level topics, transitioning of care eg “I’m aware of the next steps of my care?” and “Do I have the information I need to understand decision being made”. So it was good, those sort of forked out into health literacy. It was like all the quality improvement conversation that was had.

How did you feel, with that broad diversity of people on each table? Did everyone respect each other and work/communicate together well?

Yeah, look, I’ve been to some disrupting meetings before. I think everyone respected the space and allowed each other to be heard. So I think that was good.

Why do you think that was?

I think everyone was obviously short-listed and chosen. They’d come to the table to contribute and be respectful in that forum. I think Mary obviously got across everyone’s background before she selected them. It was a really mixed bag of people there – pathology and other sectors of health that wanted to engage with people that had some experience in these topics, as well as the consumers.

We know it is really important when working with consumers that you select the right people for the right role and set their expectations about what meetings and contributions are

expected. It sounds like Maria did a good job of that?

Yeah. We were informed what the meeting was going to be about prior. There was no, "Oh S...", surprise moment when we got there. You sort of knew what you were in for.

Was there anything that could have been changed or improved?

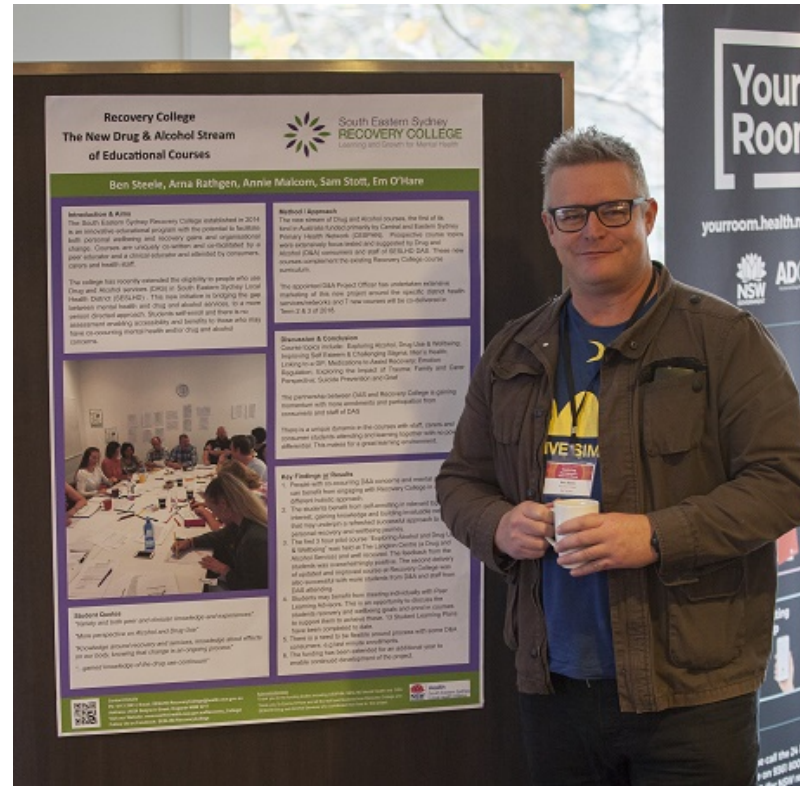
No. As I said, from what I thought would have been a pretty dry discussion, was actually the opposite. It was really a lot of innovative ideas and shared learnings. And I guess at the conclusion of it, they said that they wanted to continue on down the track in the future for further consultations with us, almost like a stage 2 or something.

So you'd be involved again?

Yeah, I've indicated to Mary, I'd be more than happy to be involved in further work on that project, with her or any other stuff with the Australian Institute of Health Innovation. I am happy to work with other researchers too.

As an example, the SESLHD Drug and Alcohol Services has an in-house research team. There's about 4 or 5 of them. The director, Nick Lintzeris, is a professor at Sydney Uni also I think, and a big advocate for research. So in my work as a consumer rep with SESLHD Drug and Alcohol, I've attended their monthly research meetings. I've made comment on their consumer facing processes and documents so they read well for a consumer. I've also

attended
APSAD and
national



conferences where research presence is the often sharing the latest trends and info in the sector

So what do you think are key skills or support you need as a consumer to be able to contribute effectively, and communicate effectively with researchers? Or the opposite – for researchers to communicate with you?

Well as a consumer worker, your lived experience personally and professionally, that's your currency. I think it's about communication. It's about process and being involved in what researchers are doing, from the early stages, even when they're

going for ethics approval, where they're actually delivering the research project. I think if it's going to be done well, and there's consumer workers available, it's almost like a partnership, in a way. As a consumer facing worker, you can actually help recruit participants for research studies, market to them, get referrals to the research team and that. There's a marketing component to it as well. If a research team really wants to be effective with their initiatives, consultation with consumers or consumer workers is going to make them more effective really, isn't it?

It's important to use non-clinical language, layman's terms, so people can actually understand what is being said. The other important bit is the loop reporting back to consumers what the result of the research has been too.

What advice would you have for other people interested in getting involved in working with researchers?

I think if people are interested in it, join alliances or memberships organizations with Health Consumers NSW, consumer health forums or the national bodies. And I spent a fair amount of time scrolling through different sites on the internet too, picking out areas of interest and sending off emails, inquiring about different things.

Would it be fair to say in your experience that you're finding opportunities, rather than the opportunities coming to you? Like researchers aren't necessarily asking you?

It's a bit of both. Sometimes you make contact with someone, just inquiring, and it leads into other avenues. Plus I've got a pretty broad network of contacts, so I'm getting approached now because people know the sort of work I'm doing. I've done few poster presentations. I've prepared a consumer profile for Health Consumers NSW. I co-wrote an article for a national addiction magazine on consumer participation, so that got published. I think the distribution of that's about 20 thousand, so you certainly get some exposure and reach from that. So different bits and pieces come up, through your network.

Thanks Ben for sharing your insights.

For anyone interested in getting more involved in research, our Research Gamechangers Facebook Group (<https://www.facebook.com/groups/Research4MeGameChangers/>) is a place you are welcome to ask questions and tap into the experience of the members already there, or share your own experiences. You can also sign up for our newsletter (<https://research4.me/newsletter/>), or register on our database (https://research4.me/volunteer_for_medical_research/) so we can send you opportunities as they arise. Alternatively, pick up the phone (<https://research4.me/contact/>) and discuss with us your questions and interests.


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